

Preference for place of care and place of death in palliative care: Are these different questions?

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Abstract:

Place of death is at times suggested as an outcome for palliative care services. This study aimed to describe longitudinal preferences for place of care and place of death over time for patients and their caregivers. Longitudinal paired data of patient/caregiver dyads from a prospective unblinded cluster randomised control trial were used. Patients and caregivers were separately asked by the palliative care nurse their preference at that time for place of care and place of death. Longitudinal changes over time for both questions were mapped; patterns of agreement (patient and caregiver; and preference for place of death when last asked and actual placed of death) were analysed with kappa statistics. Seventy-one patient/caregiver dyads were analysed. In longitudinal preferences, preferences for both the place of care (asked a mean of >6 times) and place of death (asked a mean of >4 times) changed for patients (28% and 30% respectively) and caregivers (31% and 30%, respectively). In agreement between patients and caregivers, agreement between preference of place of care and preferred place of death when asked contemporaneously for patients and caregivers was low [56% (kappa 0.33) and 36% (kappa 0.35) respectively]. In preference versus actual place of death, preferences were met for 37.5% of participants for home death; 62.5% for hospital; 76.9% for hospice and 63.6% for aged care facility. This study suggests that there are two conversations: preference for current place of care and preference for care at the time of death. Place of care is not a euphemism for place of death; and further research is needed to delineate these. Patient and caregiver preferences may not change simultaneously. Implications of any mismatch between actual events and preferences need to be explored.

Comments:

Strengths/uniqueness:

This is a well designed research project that builds on the previous literature regarding patient and family preferences with regard to location of death. The use of a patient/caregiver dyad concept to match patient and family preferences is particularly helpful.

Weakness:

The report findings are limited given this data is a subset from a larger study where the findings reported here were not the primary end points. A large number of patients were excluded from the study due to missing data, the exclusion of patients without a nominated caregiver, and the possibility that some missing data was driven by reluctance to ask questions in settings with a high risk of discordant opinions between patients and caregivers.

Relevance to Palliative Care:

This report provides a timely warning to palliative care service providers that preferences for place of care and place of death appear to be very different concepts. This emphasizes the need for palliative care programs to consider changing their outcomes of success. It can be argued that it is far more relevant to quality of care outcomes to be able to report the manner in which we meet patients' and their caregivers' preferences for care during the trajectory of the illness, rather than the simple measure of the location of death. The need to continue to update preferences and provide sensitive communication in situations of disagreement is also an important issue.